

Community-Based Care Services Fact Sheet

State And Federal Programs

Medicaid (Also see Appendices M and N)

Medicaid is a federal program (Title XIX of the Social Security Act) that pays for health services for certain of people who are poor, elderly, blind, or disabled or who are enrolled in certain programs, including Medicaid waivers. Medicaid covers children whose families receive assistance and is financed with federal and state funds. The amount varies by state.

Medicaid waivers are state-run programs that use federal funds to pay for health care for people with certain health conditions. Without Medicaid waivers, thousands of children with special health care needs would go without health care (because of their health condition, financial situation, or both) or would be institutionalized to qualify for Medicaid. Medicaid waivers permit states to use flexibility to design publicly financed health care systems outside of certain federal Medicaid statutory and regulatory requirements. Each state has different waivers with different eligibility requirements or services.

For more information on Medicaid visit the Web site:

<http://cms.hhs.gov/Medicaid/default.asp>

For more information on Medicaid Waivers visit the Web site:

<http://cms.hhs.gov/medicaid/waivers/>

EPSDT (Also see Appendix F)

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) is a provision of Medicaid that entitles eligible children to receive appropriate corrective and preventive services, supplies, and equipment (including assistive communication devices, durable medical goods, nutritional supplements, personal assistance, speech therapy, physical therapy, and occupational therapy). (See Appendix F)

For more information visit the Web site:

<http://cms.hhs.gov/Medicaid/epsdt/default.asp>

SCHIP

As Title XXI of the Social Security Act, the State Children's Health Insurance Program (SCHIP) gives grants to states to provide health insurance coverage to uninsured children, up to age 19, up to 200% of the federal poverty level (FPL). States may provide this coverage by expanding Medicaid or by expanding or creating a state children's health insurance program. Funds were available October 1, 1997. However, states do not have to participate, and they can choose to wait up to three years to implement the program without losing any funds.

For more SCHIP information, see "State Children's Health Insurance Program (SCHIP) Update" (Appendix G) or visit the Web sites:

<http://cms.hhs.gov/schip> - The Centers for Medicare and Medicaid Services (CMS) informational web site on the State Children's Health Insurance Program (SCHIP).

<http://www.aap.org/advocacy/schip.htm> The AAP provides information on the SCHIP program that includes: updates on the program, the scope of benefits, state fact sheets on what is covered and how to advocate for increased access and quality, outreach and enrollment activities, health insurance information for parents and other related resources.

Supplemental Security Income (SSI) Benefits for Children With Disabilities (Also see Appendix H)

- Administered by the Social Security Administration (SSA). Provides monthly benefits to people with limited income and resources who are age 65 or older, blind or disabled. SSI defines a child as "being under age 18, or under age 22 and in school or other training to prepare for a job, and unmarried."

Definition: The law states that a child will be considered disabled if he or she has a physical or mental condition (or a combination of conditions) that results in "marked and severe functional limitations." The condition must last or be expected to last at least 12 months or be expected to result in the child's death. And, the child must not be working at a job that is considered to be substantial work.

Requires "marked" limitations in two different areas of functioning, OR **"Extreme" limitations in** one area of functioning

For a child, this means the health problems must be "as severe as those that would keep an adult from doing any kind of work." The health problem "must limit the child from doing things that other children the same age normally can do," to the extent required by SSI rules.

What is considered:

The child's ability to perform daily activities by looking at how independently he or she can initiate, sustain, and complete activities of all sorts compared to children the same age who do not have impairments. To do this, they consider questions such as:

- What activities is the child able or not able to perform?
- Which activities are limited in comparison with those of same-age peers?
- What type and amount of help does the child need to complete age-appropriate activities?

Six Domains

- | | |
|---------------------------------------|-----------------------------------|
| 1. Cognitive and communication skills | 4. Motor |
| 2. Attending and Completing Tasks | 5. Personal Care |
| 3. Social | 6. Health and Physical Well-being |

A Special Message To Parents Of Children With Severe Disabilities

The disability evaluation process generally takes several months. However, the law includes special provisions for people (including children) signing up for SSI disability whose condition is so severe that they are presumed to be disabled. In these cases, SSI benefits are paid for up to six months while the formal disability decision is being made. (These payments can be made **only** if the child meets the other eligibility factors.)

Following are some of the disability categories in which we can presume your child is disabled and make immediate SSI payments:

- | | |
|---------------------------------|---|
| hHIV infection | hTotal Blindness |
| hTotal Deafness (in some cases) | hCerebral palsy (in some cases) |
| hDown syndrome | hMuscular dystrophy (in some cases) |
| hMental retardation | hDiabetes (with amputation of one foot) |
| hAmputation of two limbs | hAmputation of leg at the hip |

If these special payments, and it is later decided that the child's disability is not severe enough to qualify for SSI, the benefits do **not** have to be paid back.

Check with your Social Security office for information about your child's specific situation and for a full explanation of the "deeming" process.

For more information, see Appendix H, or call 1-800-772-1213 or go to the SSA website: <http://www.ssa.gov/disability>

Title V/Children with Special Health Care Needs Program (Also see Appendices D and E)

Title V programs for children with special health care needs are part of the Maternal Child Health program in every state and territory. The mandate of Title V is to provide direct service to children with special health care needs and, under OBRA '89 (Omnibus Budget Reconciliation Act), to improve the service system for this population. Each state develops and submits its own Title V plan and has a provider-consumer advisory board that sets policies and oversees programs. State programs include child health specialty clinics (community-based public and private partnerships); linkages with Part C of the Individuals with Disabilities Education Act (IDEA); home visiting; identification and referral; case management, including families as case coordinators; and rural and urban outreach programs. By law, Title V programs must be family-centered, community-based, coordinated, and culturally competent.

For more information on state Title V eligibility, visit ICHP at the Web site:
<http://cshcnleaders.ichp.edu/TitleVDirectory/default.htm>

WIC

The Women, Infants, and Children (WIC) program provides supplemental food (not total food needs), nutrition counseling, and access to health services to children, pregnant woman, and breastfeeding and postpartum women who are at nutritional risk. A physician, health care professional, or WIC officer must determine medical or nutritional risk factors.

Population Served:

The WIC target population are low-income, nutritionally at risk:

- Pregnant women (through pregnancy and up to 6 weeks after birth or after pregnancy ends). One in four new mothers participate in WIC.
- Breastfeeding women (up to infant's 1st birthday)
- Nonbreastfeeding postpartum women (up to 6 months after the birth of an infant or after pregnancy ends)
- Infants (up to 1st birthday). WIC serves 45 percent of all infants born in the United States.
- Children up to their 5th birthday.

(From <http://www.fns.usda.gov/wic/aboutwic/wicataglace.htm>)

For many programs, there are many deductions that can be made to income and assets to make one eligible. In most cases the income and assets are for the entire family household. Other eligibility requirements are that the woman must be pregnant or have a child younger than five years of age in the household. Citizenship is not necessary to qualify.

WIC is administered at the Federal level by the Food and Nutrition Service of the U.S. Department of Agriculture.

Note: If a WIC participant has a special dietary need such as a special formula or medical food, WIC requires medical documentation. "Medical Documentation is a determination by a licensed health care professional authorized to write medical prescriptions under State law that the participant has a medical condition that dictates the use of these formulas because the use of conventional foods is precluded or restricted."

For more information about WIC: <http://www.fns.usda.gov/wic/>

For WIC State Agencies: <http://www.fns.usda.gov/wic/Contacts/statealpha.HTM>

Head Start/ Early Head Start

Head Start and Early Head Start are comprehensive child development programs which serve children from birth to age 5, pregnant women, and their families. The Head Start program's mission is to improve the lives of low-income children by providing quality comprehensive child development services that are family-focused, including education, health, nutrition and mental health. The overall goal is to increase the school readiness of young children in low-income families.

Children from birth to age five from families that meet the federal poverty guidelines are eligible for Head Start/Early Head Start services. Programs throughout the country establish priorities for enrolling children based on community needs and available funds. Head Start grantees must be public or private nonprofit organizations or public school systems.

The Head Start program is administered by the Head Start Bureau, the Administration on Children, Youth and Families (ACYF), Administration for Children and Families (ACF), Department of Health and Human Services (DHHS). Head Start Bureau Web site: <http://www.acf.hhs.gov/programs/hsb/> or to find out more about Head Start in your state go to: <http://www.acf.hhs.gov/programs/hsb/hsweb/index.jsp>

Early Intervention Program for Infants and Toddlers With Disabilities

This program provides federal assistance to states to establish early intervention services for infants and toddlers with disabilities from birth through age two years, and their families. Funds are to be used to plan, develop, and implement a statewide comprehensive, coordinated, interagency, multidisciplinary system for providing early intervention services. States also may use funds to provide direct services that are not otherwise provided from other public or private sources and expand and improve current services.

State early intervention programs differ in various ways though there is a minimum set of requirements (i.e. states have some discretion in setting the criteria for child eligibility, including whether or not to serve at risk children.) States also differ concerning which state agency has been designated "lead agency" for the Part C program. For more information on this program and for state contacts visit the Web site:

<http://nectas.unc.edu/partc/partc.asp>

IDEA (a brief overview provided by The Arc)

The Individuals with Disabilities Education Act (IDEA) is a federal law mandating that all children with disabilities have available to them a free, appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living (P.L. 105-17, 1997). It provides funds to assist states in the education of students with disabilities and requires that states ensure the rights of children with disabilities and their parents are protected. IDEA also assists states in providing early intervention services for infants and toddlers with disabilities and their families.

Children ages 3 through 21 who need special education and related services because of a disabling condition are eligible. A child with a disability is defined as one with mental retardation; a hearing impairment or deafness; a speech or language impairment; a visual impairment, including blindness; emotional disturbance; an orthopedic impairment; autism; traumatic brain injury; an other health impairment; a specific learning disability; deaf-blindness or multiple disabilities. States, in agreement with local education agencies, may use the category of developmental delay to serve children ages three through nine to avoid mislabeling children.

IDEA requires that each student has an IEP (Individualized Education Program). This is a written, legal document that describes the special education and related services to be provided to the student. It also states how the child will be involved in the general curriculum and the extent, if any, to which the child will not participate with non-disabled children in a regular class. The IEP also lists supplementary aids and services to be provided to the child, or on behalf of the child, and program modifications or supports for school personnel so that the child will advance appropriately toward annual goals, progress in the general curriculum, participate in extracurricular activities and be educated with children with and without disabilities.

The full text of "The Individuals with Disabilities Act (IDEA): Eligibility, IEPs and Placement" is available at: <http://www.thearc.org/faqs/qa-idea.html>) Another resource on IDEA is the IDEA Partnerships that informs professionals, families and the public about IDEA '97 and strategies to improve educational results for children and youth with disabilities: <http://www.ideapractices.org/about/index.php>

Section 504 of the Rehabilitation Act of 1973 and Education

Section 504 prohibits discrimination on the basis of disability in programs or activities that receive federal financial assistance. The Office for Civil Rights (OCR) of the Department of Education enforces the law, prohibiting specific discriminatory activities, including the discriminatory assignment of handicapped students to segregated classes or facilities. The law applies to elementary, secondary, postsecondary schools. In elementary and secondary schools, handicapped students may be assigned to separate facilities or courses of special education only when such placement is necessary to provide them equal educational opportunity and when the separate facilities and services are comparable to other facilities and services. For more information on student placement under Section 504 and on discriminatory practices in student assignment on the basis of disability, contact OCR at 1-800/421-3481 or Email: OCR@ed.gov.

Overview of Section 504:

<http://www.ed.gov/about/offices/list/ocr/504faq.html?exp=0>

Read Section 504 of the Rehabilitation Act

<http://www.ed.gov/policy/rights/reg/ocr/edlite-34cfr104.html>

Family-To-Family Networking And Support

Family Voices

Family Voices is a national grassroots clearinghouse for information and education concerning the health care of children with special health needs. The organization monitors public and private sector health care changes that affect children and families through the collective efforts of families, a volunteer coordinator in every state, 10 regional coordinators, and a small staff working in several locations around the country. Family Voices shares the expertise and experiences of families from around the country with state

and national policy makers, the media, health care professionals, and other families. Members work in public and private hospitals, public health programs, in state capitals, in Washington, DC, serving on boards and task forces, working in partnership with health care professionals and policy makers, bringing the family perspective to policy discussions and decisions. There are almost 40,000 Family Voices members, families of children with special health needs and friends and professionals.

Family Voices is represented in every state, as well as Washington D.C., Puerto Rico, and the Virgin Islands, by Network Members, either 1 or 2 appointed State Coordinators or by Chapter Representatives. Many state organizations are run by volunteers while some are able to operate on a funded basis, generally through grants directly to their state Family Voices organization or to an associated organization. All Network Members are involved in efforts to improve the healthcare for children and youth with special health care needs.

Family Voices, Inc.
3411 Candelaria NE, Suite M
Albuquerque, NM 87107
(505) 872-4774 or (888) 835-5669
Fax: (505) 872-4780
Email: kidshealth@familyvoices.org
Internet: <http://familyvoices.org>

Family-to-Family Health Information Centers

Family-to-Family Health Information Centers provide information to families on medical homes, access to health insurance, early screening, intervention and surveillance, appropriate transition services for youth, and resources and information to empower the family to become an expert in their child's care and to plan for their future.

In June 2002, six centers were funded by the Maternal Child Health Bureau:

California - Family Voices: <http://www.familyvoicesofca.org>
Florida Institute for Family Involvement (FIFI): <http://www.fifionline.org/>
Maine Parent Federation: <http://www.mpf.org/>
Minnesota - Pacer Center: <http://www.pacer.org/health/index.htm>
Tennessee - Family Voices: <http://www.tndisability.org/familyvoices/>
Vermont- Parent to Parent of Vermont: <http://www.tndisability.org/familyvoices/>

In October, 2003, the US Department of Health and Human Services, through The Centers for Medicare and Medicaid Services, announced funding for 9 additional Family-to-Family Health Information Centers:

Alaska -Stone Soup Group: <http://www.stonesoupgroup.org/>
Colorado -Cerebral Palsy of Colorado: <http://www.cpc.org/index.html>
Indiana -The Indiana Parent Information Network, Inc.: <http://www.in.gov/ipin/>
Maryland -The Parents' Place of Maryland, Inc: <http://www.ppmd.org/>
Montana -Parents, Let's Unite for Kids: <http://www.pluk.org/>
Nevada -Family TIES of Nevada, Inc.: <http://www.familyvoices.org/st/NV.htm>
New Jersey -Statewide Parent Advocacy Network of NJ, Inc.: <http://www.spannj.org/>
South Dakota -South Dakota Parent Connection: <http://www.sdparent.org/>
Wisconsin -Family Voices of Wisconsin: <http://www.wfv.org/fv/>

For more information visit the Family Voices web site:

<http://www.familyvoices.org/f2fcoop.htm>